



Independent  
Advisory  
Council  
to the **ndis**



Independent Advisory  
Council to the NDIS

# Annual Report

2022  
2023

## Our acknowledgement and commitment to accessibility

The Independent Advisory Council (IAC) Annual Report is made possible thanks to the efforts of people with disability. This report acknowledges and pays respects to fellow Australians with disability.

We, the IAC, reconfirm our commitment to the mission of the National Disability Insurance Scheme (NDIS), to contribute to a just and inclusive Australia where all can reach their full potential and live ordinary lives.

We also acknowledge the Traditional Owners and Custodians of the country throughout Australia, and their continuing connection to land, sea, and community. We pay our respects to their Elders, past, present, and emerging.

In our commitment to accessibility, we have written this Annual Report in an easier to understand way. Some words you may not understand have been highlighted in **bold**. They are included in a Word list at the end of this report that explains what these words mean. There is also a list of commonly used Acronyms at the end of this report.

# Contents

<b>1. Principal Member's review</b>	<b>4</b>
<b>2. Our important advisory role</b>	<b>7</b>
2.1 About the IAC's membership	8
2.2 About IAC Members	9
2.3 Others who support the IAC	14
<b>3. Reference Groups of the IAC</b>	<b>16</b>
3.1 Children, Young People and Families Reference Group	17
3.2 Equity and Inclusion Reference Group	17
3.3 Home and Living Reference Group	18
3.4 Intellectual Disability Reference Group	18
<b>4. My view: representing intellectual disability in the IAC</b>	<b>19</b>
<b>5. Our priorities</b>	<b>21</b>
5.1 Our Operating Model defines how we deliver advice	21
5.2 Our Work Plan	23
<b>6. Celebrating a decade as the voice of participants in the NDIS</b>	<b>24</b>
<b>7. Promoting our work</b>	<b>27</b>
<b>8. Year in review</b>	<b>29</b>
<b>9. Advice to the NDIA Board and input into NDIA co-design</b>	<b>32</b>
9.1 Advice to the NDIA Board	32
9.2 Input into NDIA co-design	34
<b>10. Word list</b>	<b>36</b>
10.1 Acronyms	37



Cover photo: 16 year old NDIS participant Alyssa is now living a full life with the assistance of a strong NDIS support base, helping her achieve her goals so she is more independent in the future. Her mum Melissa, hopes for Alyssa's growing independence to continue to the point where she can be in paid employment in the future.

[Read Alyssa's story on the NDIS website.](#)

# 1. Principal Member's review



It is my pleasure to present the [Independent Advisory Council \(IAC\)](#) Annual Report for 2022-23. The purpose of this report is to let the disability community and Australian people know about the important work the IAC has done over the past year. We want to be open and genuine with you about our work.

Above: Photo of Ms Leah van Poppel, Principal Member of the Independent Advisory Council to the NDIS and National Disability Insurance Agency (NDIA) Board Member.

The Annual Report outlines the advice and achievements of the IAC and its 4 Reference Groups from 1 July 2022 to 30 June 2023. This year, on the 10th anniversary of the NDIS and IAC, we stayed true to our statutory role and commitment to deliver independent advice to the [Board of the National Disability Insurance Agency \(NDIA\)](#).

To deliver our advice, we have been guided by our [2022-23 Work Plan](#) and our [Operating Model](#). The **Work Plan** and **Operating Model** maintain the accountability, integrity, and performance of our work.

We have worked collaboratively with the NDIA to ensure that the **Agency Responses** to our advice are developed to maximise effective implementation of our recommendations.

This year, we have continued to refine and further develop some advice from last year's Work Plan. This includes our advice about improving equity and inclusion in the [National Disability Insurance Scheme \(NDIS\)](#) and behaviour supports. We also decided to reprioritise the advice about participants who are ageing.

## 1. Principal Member's review

I was pleased, that after deep collaboration with community leaders, we finalised the advice [Improving equity in the NDIS \(DOCX 307KB\)](#). We sent this advice alongside the Agency Response to the NDIA Board in March 2023. Importantly, the Board approved the Agency Response to the advice and supported all advice recommendations.

In September 2022, we prioritised the development of the advice 'Improving the NDIS for children and young people: the importance of being guided by their voice'. We did this to ensure that urgent gaps in NDIS supports for children and young people were known to the Board. The IAC endorsed this advice in May 2023.

This year, we have worked alongside the disability community, including Disability Representative and Carer Organisations (DRCOs), to support the [NDIA's vital work toward co-design](#). IAC representatives, including IAC and IAC Reference Group Members, have worked on **co-design** steering committees to guide and strengthen the NDIA's work about:

- information gathering for access and planning
- home and living
- supported decision making
- participant safeguards.

In May 2023, the Australian Government committed to [getting the NDIS back on track](#). As part of this, the IAC has been working with the NDIA and representatives from the disability community to [co-design 6 key initiatives](#). This is to ensure that the NDIS delivers better outcomes for participants, and in the process, help secure the ongoing **sustainability** of the Scheme.

Amidst the flurry of co-design, the IAC endorsed 'Operationalising **intersectionality**', our guide for applying an intersectional lens to all our advice and work. We have also engaged with the work of the [NDIS Review](#) and the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#).

Suffice to say, it has been a big year for us. I want to thank my fellow IAC and IAC Reference Group Members, the NDIA Board, and NDIA staff, for the passion and contribution they have shown the IAC over the past year.

I am grateful for the high regard and respect held for IAC's advice across various levels of **governance**, oversight, and government. I thank Mr Kurt Fearnley AO, NDIA Board Chairperson, Ms Rebecca Falkingham PSM, NDIA Chief Executive Officer, the Honorable Bill Shorten MP, Minister for the NDIS, and state and territory governments, for the commitment they have shown the IAC this year.

## 1. Principal Member's review

As is the case when you look back on a year, you often reflect on achievements made, while knowing there is still work to do. Our aim remains that participants live a life of their choice, through NDIS supports that allow them to be independent, safe, and included in their communities.

The IAC remains committed to advising and engaging the NDIA Board, NDIA staff and the disability community to improve the NDIS for current and future generations of participants.

'As is the case when you look back on a year, you often reflect on achievements made, while knowing there is still work to do. Our aim remains that participants live a life of their choice, through NDIS supports that allow them to be independent, safe, and included in their communities.'

Ms Leah van Poppel, Principal Member of the Independent Advisory Council to the NDIS and NDIA Board Member



**Ms Leah van Poppel**

**Principal Member of the Independent  
Advisory Council to the NDIS and NDIA  
Board Member**

## 2. Our important advisory role

The IAC was established as part of the [National Disability Insurance Scheme \(NDIS\) Act 2013](#). Our statutory role is to give advice to the NDIA Board, both at their request and on our own initiative.

We bring lived experiences of disability into the boardroom of the NDIA through our [advice](#). Section 144(1) of the NDIS Act outlines that our advice should draw attention to the most important issues affecting people with disability. Our advice allows us to speak up for people with disability and put participants at the centre of the NDIS.

Our advice is highly regarded and respected because it connects the Board to the experiences of people with disability. We shine a light on priority disability issues and opportunities across Australia that we think the Board should know about. We frame our advice for the Board to consider as part of its function and running of the NDIA. Our aim is to make the NDIS better, by shaping NDIS services, systems and processes.

Below: Photo of IAC Members working at an IAC meeting.



## 2. Our important advisory role

On top of providing advice to the Board, the IAC is sought after to share its advice with NDIA business areas and external **stakeholders**. This is especially the case with the NDIA's co-design work. Co-design has allowed our members to provide their know-how as the NDIA makes improvements to NDIS policies, systems and services.

As part of our own procedures, we have established [4 Reference Groups](#) to further strengthen and guide our advice. Our Reference Groups also help us represent the diversity of people with disability as part of the IAC. They add valuable expertise to the IAC's advice around the areas of:

- children, young people, and families
- equity and inclusion
- home and living
- intellectual disability.

### 2.1 About the IAC's membership

IAC Members bring their advice to life through their skills, experience and knowledge about different areas of disability. IAC Members also know a lot about the NDIS, including the detail of how it works. They understand the services and supports available across Australia, including rural and remote areas.

Most current members are people with disability or have broad-ranging lived experience that helps the IAC fulfil its statutory role. Our members come from most

Australian states and territories. We also have First Nations and culturally and linguistically diverse (CALD) representation, to ensure we promote diversity.

The Minister for the NDIS works with state and territory governments to appoint our members, in line with section 147 of the NDIS Act.

Current [IAC Members](#) at 30 June 2023, include:

- Ms Leah van Poppel, Principal Member and NDIA Board Member
- Ms Kerry Allan\*
- Dr Sharon Boyce
- Adjunct Associate Professor Jennifer Cullen
- Dr Leighton Jay
- Ms Sylvana Mahmic
- Ms Tricia Malowney OAM
- Mr James Manders
- Ms Sam Paior
- Ms Liz Reid AM
- Dr George Taleporos
- Mr Mark Tonga.

This year, Mr Gavin Burner attended IAC meetings to strengthen our representation of people with intellectual disability. Mr Burner is a member of the IAC's Intellectual Disability Reference Group.

Dr Ben Gauntlett also supported the IAC as Expert Adviser, alongside Ms Belinda Epstein-Frisch AM, the IAC's Independent Consultant. This year, Mr Alan Blackwood supported Ms Epstein-Frisch in her role.

\*Ms Allan was on a leave of absence throughout 2022-23.



## 2. Our important advisory role

### 2.2 About IAC Members



#### **Ms Leah van Poppel, IAC Principal Member and NDIA Board Member**

Ms Leah van Poppel connects the work of IAC with the NDIA. As the IAC Principal Member, she guides the direction of our advice and our meetings. In her role as NDIA Board Member, Ms van Poppel is also a member of the Sustainability Committee. In this committee, she focuses on ways to keep the NDIS running for future generations.

Ms van Poppel's experience includes state and federal government policy work. She is the current Chair of the Victorian NDIS Community Advisory Council. She is also a woman with disability and an NDIS participant.

[Read more about Ms Leah van Poppel's experience.](#)



#### **Ms Kerry Allan, IAC Member**

Ms Kerry Allan brings experience in disability leadership and advocacy to her role on the IAC. Based in Western Australia, she also serves on the Governance Steering Committee for National Disability Services' 'WA Ready to Go Home project'. Here she helps find solutions to hospital discharge issues impacting people with disability.

Ms Allan was born with cerebral palsy, and her lived experience has informed her IAC work since 2017. This year she took a leave of absence from the IAC.

[Read more about Ms Kerry Allan's experience.](#)

## 2. Our important advisory role / 2.2 About IAC Members



### **Dr Sharon Boyce, IAC Member and Home and Living Reference Group Member**

Dr Sharon Boyce is an educator, author and advocate who lives with disability. Dr. Boyce has over 30 years' experience across diverse disability community groups. As part of her roles on the IAC, she helps us understand the complexity of disability in Australia.

Dr Boyce is Chair of the Queensland Disability Advisory Council. She is also Vice President of Physical Disability Australia.

[Read more about Dr Sharon Boyce's experience.](#)



### **Adjunct Associate Professor Jennifer Cullen, IAC Member and Equity and Inclusion Reference Group Co-Chair**

Adjunct Associate Professor Jennifer Cullen is an academic and proud First Nations descendent. Her First Nations networks and understanding of rural and remote disability supports helps to inform her roles on the IAC.

As CEO of Synapse, Associate Professor Cullen leads Australia's top brain injury organisation. She is also an advocate for First Nations peoples. Her work covers justice, health, and disability across state and federal levels.

[Read more about Adjunct Associate Professor Jennifer Cullen's experience.](#)



### **Dr Leighton Jay, IAC Member and Home and Living Reference Group Co-Chair**

Dr Leighton Jay has experience in the disability and academic sectors of Western Australia. He brings his passion for creating communities that value the voice of people with disability to his roles on the IAC.

As Company Director and Principal at Sotica, he advises on policies and services that impact people with disability. Dr Jay is also a parent of a NDIS participant with complex support needs.

[Read more about Dr Leighton Jay's experience.](#)

## 2. Our important advisory role / 2.2 About IAC Members



### **Ms Sylvana Mahmic, IAC Member and Children, Young People and Families Reference Group Co-Chair**

Ms Sylvana Mahmic brings her advocacy skills, in the areas of early childhood intervention and self-management in New South Wales, to her roles on the IAC.

As CEO and Board Member of Plumtree, she supports families and children with disability to gain independence and take part in their community. Ms Mahmic is also a part of the National Early Childhood Strategy Expert Advisory Panel. Her experience of disability comes from her son who is a NDIS participant.

[Read more about Ms Sylvana Mahmic's experience.](#)



### **Ms Tricia Malowney OAM, IAC Member and Equity and Inclusion Reference Group Member**

Ms Tricia Malowney OAM is a person with disability and human rights advocate based in Victoria. In addition to her roles with the IAC, she is a part of NDIA's Specialist Disability Accommodation (SDA) Price Review Expert Panel.

She has experience as a consultant, promoting inclusion across health, justice and family violence sectors to government and non-government agencies alike. She is also Chief Accessibility Advocate for the Victorian Department of Transport.

She is passionate about removing intersectional disadvantage for people with disabilities.

[Read more about Ms Tricia Malowney's experience.](#)

## 2. Our important advisory role / 2.2 About IAC Members



### **Mr James Manders, IAC Member**

Mr James Manders advocates for the inclusion of people with disability in the workforce as part of his role on the IAC. He is a leader in accessible digital media and is interested in ways assistive technology can help with inclusion.

Mr Manders is Independent Director and Board Chair at RPHA, a radio station for vision diverse people. He has over 25 years' experience as an investment banker. He is based in the Australian Capital Territory and lives with disability.

[Read more about Mr James Manders' experience.](#)



### **Ms Sam Paior, IAC Member and Intellectual Disability Reference Group Member Co-Chair**

Ms Sam Paior brings a strong skill set across advocacy, service provision and support coordination to her roles on the IAC. She is passionate about human rights, inclusion, and clear communication for people with disability.

With over 20 years' experience in the disability sector, Ms Paior is also CEO of The Growing Space. They provide support coordination and training to NDIS participants and their families.

Ms Paior a single parent of 2 young adult NDIS participants, based in South Australia. She has a hearing impairment.

[Read more about Ms Sam Paior's experience.](#)

## 2. Our important advisory role / 2.2 About IAC Members



### **Ms Liz Reid AM, IAC Member and Children, Young People and Families Reference Group Member**

Ms Liz Reid AM is passionate about inclusion and equal opportunity. In addition to her roles with the IAC, Ms Reid is a member the NDIA's First Nations Advisory Council.

She is CEO of YouthWorX NT, who help young Territorians achieve social and career success. Ms Reid has over 25 years' experience in community, disability, and social justice systems. She is also an advocate for **trauma-informed** care and First Nations people.

[Read more about Ms Liz Reid's experience.](#)



### **Dr George Taleporos, IAC Member and Home and Living Reference Group Member**

Dr George Taleporos brings his skills as an advocate for disability rights and self-directed supports to his roles on the IAC. He is a strong voice for people with disability and works on the Summer Foundation's podcast 'Reasonable and Necessary'.

Dr Taleporos is a Board Member of InLife, who build teams specifically to support people with disability. He is also Chair of the Mabel Disability Advisory Committee and Every Australian Counts.

Dr Taleporos is a person with physical disability and high support needs based in Victoria.

[Read more about Dr Taleporos' experience.](#)

## 2. Our important advisory role / 2.2 About IAC Members



### **Mr Mark Tonga, IAC Member and Home and Living Reference Group Member**

Mr Mark Tonga is passionate about inclusion of all people with disability. As part of his roles on the IAC, he advocates for fairness, collaboration, and community engagement.

An accountant by profession, he holds several roles within the New South Wales disability community and not-for-profit sector. He collaborates across his networks to influence policies and supports for people with diverse disabilities.

Mr Tonga acquired tetraplegia as a 35-year-old following a rugby incident.

[Read more about Mr Mark Tonga's experience.](#)

## 2.3 Others who support the IAC



### **Dr Ben Gauntlett, IAC Expert Adviser**

Dr Ben Gauntlett serves as Expert Adviser and has worked with IAC since May 2019. He brings his experience as the Disability Discrimination Commissioner at the Australian Human Rights Commission to the IAC.

Dr Gauntlett's 5-year term as Disability Discrimination Commissioner ended on 30 June 2023, and he subsequently stepped down from his work with the IAC.

Dr Gauntlett is Chair of Australia's Disability Strategy Advisory Council. He has lived experience of disability and is quadriplegic.

[Read more about Dr Ben Gauntlett's experience.](#)

## 2. Our important advisory role / 2.3 Others who support the IAC



### **Ms Belinda Epstein-Frisch AM, IAC Independent Consultant**

Ms Belinda Epstein-Frisch AM has been the IAC's Independent Consultant since 2014. She works with the IAC and IAC Reference Groups to bring our advice to life for the NDIA Board.

Her experience is in advocacy, community development and social policy for people with disability. She has also been a member of ministerial advisory councils on disability reform and education at state and national level.

With close to a decade of experience working with the IAC, Ms Epstein-Frisch will step down from her role in the first quarter of 2023-24.

[Read more about Belinda Epstein-Frisch's experience.](#)



### **Mr Gavin Burner, IAC Intellectual Disability Reference Group Member**

Mr Gavin Burner joined IAC meetings this year to strengthen representation of people with intellectual disability. He is an IAC Intellectual Disability Reference Group Member, and an advocate for people with intellectual disability in rural and remote areas.

Mr Burner is also Co-Chair of the South Australian Council on Intellectual Disability, where he is an Inclusion Advisor. He is passionate about peer networks and has worked as a Program Assistant at the Camden Community Centre.

### 3. Reference Groups of the IAC

IAC [Reference Groups](#) are an invaluable source of further expertise for our advice. They have been determined as part of our own procedures, to give advice and feedback in relation to issues and opportunities across 4 focus areas. They enrich our advice and are an additional source of expertise for the NDIA.

Our [Reference Groups](#) boast a representative membership, comprising mostly people with disability or lived experience. This includes representation from First Nations and CALD peoples. Our members are carers, disability experts, researchers and community representatives.

IAC Reference Groups include:

- Children, Young People and Families Reference Group
- Equity and Inclusion Reference Group
- Home and Living Reference Group
- Intellectual Disability Reference Group.

Below: Photo of IAC Members working at an IAC meeting.





### 3. Reference Groups of the IAC

#### 3.1 Children, Young People and Families Reference Group

The [Children, Young People and Families Reference Group](#) aims for young people with disability to have NDIS supports that promote freedom and choice. The Reference Group wants families of children with disability to be supported and involved in their community.

Its membership includes:

##### **Co-Chairs**

- Leah van Poppel
- Sylvana Mahmic.

##### **IAC Member representatives**

- Sam Paior
- Liz Reid AM.

##### **Reference Group Members**

- Katharine Annear
- Tash Binder
- Jake Briggs
- Ara Cresswell
- Abraham Darouiche
- Catherine Dunn
- Karina Enks
- Melo Kalemkeridis
- Mary Sayers
- Professor Les White
- Professor Andrew Whitehouse.

#### 3.2 Equity and Inclusion Reference Group

The [Equity and Inclusion Reference Group](#) focuses on how to make the NDIS more inclusive. Their goal is to create equal opportunity, fairness and transparency in the NDIS.

They bring the experiences of people with diverse backgrounds, including:

- First Nations communities
- CALD communities
- Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual Plus (LGBTIQA+) communities.

Its membership includes:

##### **Co-Chairs**

- Leah van Poppel
- Adjunct Associate Professor Jennifer Cullen.

##### **IAC Member representative**

- Tricia Malowney OAM.

##### **Reference Group Members**

- Margherita Coppolino
- Jadnah Davies
- Faye Dickson
- Judith Drake
- Benjamin Garcia-Lee
- Catherine McAlpine
- Nigel Pernu
- Suzy Trindall
- Felix Walsh
- Barbel Winter.

## 3. Reference Groups of the IAC

### 3.3 Home and Living Reference Group

The goal of the [Home and Living Reference Group](#) is for people with disability to have choice in how and where they live. They advise the IAC on how the NDIS can improve home and living supports to help participants do things for themselves.

Its membership includes:

#### Co-Chairs

- Leah van Poppel
- Dr Leighton Jay.

#### IAC Member representatives

- Dr Sharon Boyce
- Adjunct Associate Professor Jennifer Cullen
- Dr George Taleporos
- Mark Tonga.

#### Reference Group Members

- Alan Blackwood
- Liz Dutton
- Rebecca Evans
- Peter Gregory
- Grace Mills
- Associate Professor Mary-Ann O'Donovan
- Leanne Pearman
- Pat Sutton
- Peter Tully
- Robbi Williams.

### 3.4 Intellectual Disability Reference Group

The [Intellectual Disability Reference Group](#) wants people with intellectual disability to live a life of their choice. Their work promotes the use of NDIS supports for independence and community inclusion for people with intellectual disability.

Its membership includes:

#### Co-Chairs

- Leah van Poppel
- Sam Paior.

#### IAC Member representatives

- Dr Leighton Jay.

#### Reference Group Members

- Paige Armstrong
- Gavin Burner
- Marissa Carlyon
- Nathan Despott
- Angus Graham OAM
- Judy Huett
- Brodie McElroy
- Leonie McLean
- Professor Sally Robinson
- Jim Simpson
- Sarah Sutton
- Justen Thomas
- Catherine Viney
- Angela Yee.

## 4. My view: representing intellectual disability in the IAC



Mr Gavin Burner is a valued member of the Intellectual Disability Reference Group. He has also attended IAC meetings this year to ensure we best represent people with intellectual disability. We talked to him about his important contribution to the IAC.

Above: Mr Gavin Burner, IAC Intellectual Disability Reference Group Member.

### **Why is the IAC important to you?**

The IAC is important to me because it is made up of members from different backgrounds, people from all over the country, who are all working together to help make the lives of people with disability in Australia better.

### **Tell us about your first IAC meeting and how did you feel?**

I felt a bit scared, and I remember asking myself 'how did I get here?!', because it is a dream come true for me. That first meeting made me think about all the people who've believed in me and supported me over the years. They helped me believe that I can actually have a career, not just a job. I looked around the meeting table

#### 4. My view: representing intellectual disability in the IAC

that day, seeing all the Members who I really respect, and it felt really good to be included as an expert in intellectual disability. I feel very proud to give advice about the issues people with intellectual disability face.

##### **How does it feel to tell the IAC about what is happening for people with intellectual disability?**

When I tell the IAC about what is happening for people with intellectual disability, I feel like I am being heard. But I also feel like the voices of all those people I advocate for are being heard. I try to put my point across, plant the seed and hopefully it will grow into positive change for people with intellectual disability in the NDIS.

##### **How do you prepare for an IAC meeting?**

I read all the information about the meeting topics. I have preparation meetings with my support worker and another one with the IAC Secretariat. I try to break down all the meeting topics to make it really simple for me and think about what I want to say about those topics.

I also work closely with my networks in the disability community to ask them about the good and bad things they're hearing about the NDIS. I also get a lot of this information about the community from my work at the South Australian Council for Intellectual Disability. I report on these things at an IAC meeting.

##### **What do you want to see the NDIA do to improve supports for people with intellectual disability?**

I want all NDIS plans to be in Easy Read so that people with intellectual disability understand their supports and how much money they have in their plan. I really want that to be the norm for all people with intellectual disability in the NDIS.

##### **What is the key for people with intellectual disability to live good lives?**

I think people with intellectual disability need more information and education about how to be healthy and safe, so they can live a long, happy and independent life. I would like to see more information linkages and capacity building grants to help intellectual disability communities throughout Australia. I think peer groups, workshops and community connections are the key to supporting people with intellectual disability.

## 5. Our priorities

Our advice is our most important output, and we work hard so that it creates the positive impact we want. Our [Operating Model](#) defines how we work so that we can achieve our aims.

It makes sure our advice aligns with issues and opportunities the NDIA may need guidance on. We also use our operating model to guide how we contribute to other NDIA work.

### 5.1 Our Operating Model defines how we deliver advice

Our Operating Model outlines the 4 steps we take to create, deliver and progress our advice.



#### 1. Identify and prioritise:

- The NDIA Board makes a formal request for our advice each financial year.
- We think about the advice they are after alongside the priorities we have already identified.
- We develop and endorse our Work Plan. This is a plan about the advice and work we will focus on over the next year.



#### 2. Mobilise:

- We decide which part of the NDIA can implement our advice the best.
- We get expert advice from our networks.
- We organise literature reviews and research. We also engage with people who would be impacted by any changes we advocate for.
- The IAC and IAC Reference Groups consider our draft advice.
- The IAC endorses the advice.



**3. Advise:**

- The NDIA makes an Agency Response that outlines what it will do about our advice. This includes recommendations that it will implement.
- We submit the advice and Agency Response to the NDIA Board, who refer our work to the [Disability Reform Ministerial Council \(DRMC\)](#). The DRMC is the Ministerial Council for the purposes of the NDIS Act.



**4. Implement:**

- We publicly release our advice, so that the NDIA and other stakeholders understand our recommendations.
- The NDIA implements our advice. They give the IAC and NDIA Board regular reports on how the implementation process is going.
- Sometimes the NDIA will engage the IAC about implementation activities related to our advice.

## 5. Our priorities

### 5.2 Our Work Plan

Our Work Plan outlines the work the IAC will do over a year. When developing our Work Plan, we consider:

- The priorities of the IAC and its Reference Groups
- Requests the NDIA Board has made for our advice
- The priorities outlined in the NDIA Corporate Plan
- Other priorities from the government and disability sectors. This includes current issues of concern and the DRMC's priorities.

#### **Our priorities for 2022-23 were to:**

- Put participants at the centre of the NDIS by:
  - Creating and using an intersectional approach to our work
  - Amplifying the voice of children and young people
  - Understanding the experiences of ageing participants and the role the NDIS plays in supporting them.
- Support effective NDIS plans that create positive outcomes for participants by:
  - Co-designing a Participant Safeguards Policy
  - Co-designing a Supported Decision-Making Policy
  - Engaging people with disability in a new framework for delivering home and living supports
  - Co-designing work for Information Gathering for Access and Planning
  - Developing advice on behaviour supports.
- Work with government agencies outside the NDIA.
- Communicate clearly and accessibly.
- Check to see how the NDIA is applying our advice.
- Continue working collaboratively with the NDIA.

We focus on areas where our advice will have meaningful, **systemic**, and long-lasting impact. Our advice looks at the whole system of disability support and how it can create better outcomes for people with disability.

Our Work Plan is always flexible and may change if we identify new priorities throughout the year.

## 6. Celebrating a decade as the voice of participants in the NDIS



2023 marks a significant milestone: a decade of the NDIS and the IAC's representation of the participant voice. Ms Belinda Epstein-Frisch AM has played an important role in supporting the IAC for a major part of this journey. She generously shares her reflections as Independent Consultant to the IAC.

### **Can you tell us about the evolution of the IAC's role and influence over the years?**

The IAC's role and its relationship with the NDIA has seen significant improvement over time. In the early NDIS rollout phase, alignment between NDIA and IAC priorities was lacking. Now a strengthened alignment exists, with all IAC advice being thoroughly reviewed by the Board, accompanied by an Agency Response, as mandated by the NDIS Act. Importantly, the NDIA actively seeks IAC's input to shape strategies, policies and practices, signifying both parties' commitment to empowering Australians with disabilities.

Above: Ms Belinda Epstein-Frisch AM, IAC Independent Consultant.



## 6. Celebrating a decade as the voice of participants in the NDIS

### **The IAC holds a pivotal statutory role. Could you elaborate on its significance?**

The IAC's statutory role strengthens the disability community's voice at the governance level of the NDIS. Most importantly, the legislation allows the IAC to offer advice proactively. This ability empowers the IAC to bring concerns from the disability community, often not on the Agency's radar, to the NDIA Board's attention. To me, this exemplifies genuine inclusion, placing the voices of people with disabilities and their families at the heart of the NDIS.

### **Could you highlight a standout piece of IAC advice and its impact?**

The 2021 advice [Strengthening Scheme reforms to access and planning \(DOCX 155KB\)](#) holds significant impact. In response to equity and sustainability concerns, the NDIA started work on independent assessments in 2019. This triggered apprehension in the disability community, eroding trust.

Acting as a critical friend, the IAC worked closely with the Minister and NDIA Board, organising consultations that underpinned the advice and helped to rebuild community relations. This advice prompted the Minister to pause independent assessments and started the NDIA on its co-design journey, which continues on today.

### **Tell us about your role with the IAC?**

My role is to assist with IAC advice development, by incorporating research, IAC and Reference Group Members' insights, and subject matter expertise. The independence of this role from the Agency remains crucial to ensure IAC advice remains authentic, representing IAC Member and community perspectives without influence from the NDIA. This independence positions the IAC as the 'critical friend' of the NDIA, its Board and the Minister.

### **The IAC's diverse membership has shifted over time, and you have worked with 4 Principal Members and through various IAC membership changes. What have you learnt from this?**

The IAC's leadership and membership has reflected the times. Different Principal Members brought unique perspectives. Rhonda Galbally AC was a visionary leader who aimed to ensure community expectations were reflected in the NDIS.

John Walsh AM, co-author of the 2011 Productivity Commission's [Disability Care and Support report](#), establishing the NDIS, ensured the IAC raised with the NDIA Board the importance of capacity building in achieving participants outcomes and a sustainable NDIS.

## 6. Celebrating a decade as the voice of participants in the NDIS

Robyn Kruk AO worked hard to strengthen the voice of people with disability in the NDIS and guided the IAC through difficult times of 2021 Scheme Reforms. Today, Leah van Poppel brings to the IAC her strong links with the disability community and works actively to strengthen NDIA processes that ensure the voice of people with disability is pivotal to decisions around the design and delivery of the NDIS.

IAC's membership characteristics are enshrined in the NDIS Act, for enhanced diversity. The IAC places high value on ensuring its advice reflects a diverse and intersectional approach, based on evidence. We also use our Reference Groups as an important tool to strengthen the diversity of voices that contribute to IAC advice.

### **What is the IAC's impact on NDIS design and delivery?**

The advice [Reasonable and necessary support across the lifespan: An ordinary life for people with disability \(PDF 1MB\)](#)

was transformative. At the NDIS's inception in 2013, it shifted focus from crisis-driven support to an insurance approach centred on building capacity. This advice introduced the concept of an 'ordinary life,' advocating for support fostering relationships, belonging, autonomy, and community engagement. A decade later, these principles endure, fostering positive change for participants.

### **Final parting words?**

It has been an enormous privilege to serve in this role with IAC. As a long-term advocate, this role allowed me to continue to seek the best possible outcomes for people with disability, working internally at the highest level. I want to pay tribute to the enormous dedication and insights of IAC and Reference Group members. I have learnt an enormous amount and feel confident that the IAC will continue to be the independent critical friend to the NDIA, Board and Minister.

‘It has been an enormous privilege to serve in this role with IAC. As a long-term advocate, this role allowed me to continue to seek the best possible outcomes for people with disability, working internally at the highest level.’

Ms Belinda Epstein-Frisch AM, IAC Independent Consultant.

## 7. Promoting our work

This year we have continued to share accessible information about our work to raise awareness and understanding of the IAC. We want to make sure that the IAC's important statutory role, advice and expert membership is well known to the NDIA and disability community. We are also passionate about accessible communications and engagement; that is why we use plain English and Easy Read.

We have:

- Released 21 bulletins about IAC and IAC Reference Group meetings to the public. We also delivered Easy Read translations for our bulletins; this includes online versions with text to voice capability.
- Implemented Easy Read meeting packs for the Intellectual Disability Reference Group's face-to-face meetings. We have paired these with a meeting pre-briefing, to better explain what will be discussed at meetings, so that all members can engage with the information equally.

Below: Photo of IAC Members working at an IAC meeting.



## 7. Promoting our work

- Released and promoted IAC's Work Plan to the public. This is because we want to be open and accountable about IAC advice and priority work. We also delivered Easy Read translations for our Work Plan; this includes online versions with text to voice capability.
- Released our Annual Report to the public, to promote and highlight IAC's annual achievements. We also delivered Easy Read translations for our Annual Report; this includes online versions with text to voice capability.
- Updated online platforms to ensure up to date and accessible information, including the IAC website, NDIA internal communications platforms, and other channels.
- Continued to find new ways to engage with the disability community across Australia, through community update presentations led by our Principal Member. We have also sought new ways to engage with the NDIA, the Minister for the NDIS, DRMC, and state and territory disability advisory councils, as well as other disability organisations.

This year we also remained committed to our plans to redesign and redevelop the [IAC website](#). We want our website and its content to meet the highest accessibility standards and user experience.

## 8. Year in review



### 2022

#### July

- The NDIA introduces [new legislative amendments](#) to the NDIS Act. Subsection 147(3) notes that the appointment of a Principal Member to the IAC must also be a member of the NDIA Board.
- IAC starts co-design work with the NDIA on a new Home and Living Framework.

#### August

- The IAC makes progress in co-designing a new Supported Decision-Making Policy.
- The IAC Home and Living Reference Group holds its third meeting for 2022-23, focusing on the [SDA Pricing Review](#), SDA operational guideline and Individualised Living Options (ILO) review.

#### September

- The Hon Bill Shorten, Minister for the NDIS, attends his first official IAC meeting to discuss IAC and ministerial priorities.
- The IAC Children, Young People and Families Reference Group meets to start development of 'Improving the NDIS for children and young people: the importance of being guided by their voice' advice.
- Mr Kurt Fearnley AO appointed Chair of the Board of the NDIA. The NDIA Board also welcomes new members Dr Graeme Innes AM and Ms Maryanne Diamond AO. Ms Rebecca Falkingham PSM, accepts the role of NDIA CEO.

#### October

- The Australian Government launches the NDIS Review, with IAC starting engagement with the [Independent Review Panel](#).
- The IAC Intellectual Disability Reference Group holds its second meeting for 2022-23 and discussed progress on the NDIA's Supported Decision-Making Policy and Home and Living Framework.



## 2022

### November

- The IAC releases its [2022-23 Work Plan \(DOCX 84KB\)](#). This outlines 6 priorities that the IAC will focus on during the financial year.
- The IAC welcomes Mr Fearnley, the new NDIA Board Chairperson, and Ms Falkingham, the new NDIA CEO, who attend their first official IAC meeting.
- The IAC discuss the co-design work relating to testing home and living solutions with underrepresented people and the NDIA's draft Home and Living Framework.
- The IAC Equity and Inclusion Reference Group holds its first meeting for 2022-23 to discuss the NDIA's First Nations Strategy, CALD Strategy and LGBTIQ+ Strategy.

### December

- The IAC endorses 'Operationalising Intersectionality', a guide for applying an intersectional lens to our work.
- IAC holds further discussions about the 'Improving the NDIS for children and young people: the importance of being guided by their voice' advice.



## 2023

### February

- The NDIA reports to the IAC about how its advice recommendations are being progressed.
- The Children, Young People and Families Reference Group meets to provide feedback on recommendations about the IAC's 'Improving the NDIS for children and young people: the importance of being guided by their voice'.

### March

- The NDIA Board notes IAC's [Improving equity in the NDIS \(DOCX 307KB\)](#) advice and Agency Response.



## 2023

### April

- The IAC meets in Hobart, holding its first in-person meeting since the COVID-19 pandemic.
- The IAC talks to Tasmanian DRCOs and partners in the community about their experience with the local testing of PACE, the new NDIS customer relationship management system.
- The NDIA publicly releases its new [Participant Safeguarding Policy](#). This Policy marks the delivery of one of the NDIA's first major co-design projects with the IAC and disability community.

### May

- The IAC endorses its 'Improving the NDIS for children and young people: the importance of being guided by their voice' advice.
- The IAC discuss their Work Plan for 2023-24.
- IAC starts work on co-designing 6 key initiatives as part of the [Australian Governments' NDIS reform work](#), to ensure the NDIS delivers better outcomes for participants.
- The IAC works on proposed themes for submission to the NDIS Review.
- The IAC Children, Young People and Families Reference Group provides feedback to the NDIS Review's Independent Review Panel.
- The NDIA releases its [Supported Decision-Making Policy](#). This Policy, a result of one of the Agency's co-design projects, had its genesis from the IAC's June 2021 advice [Choice and control to safely live a good life of belonging and citizenship \(DOCX 1MB\)](#) and early work done by the IAC Intellectual Disability Reference Group.

### June

- IAC sends [Improving equity in the NDIS \(DOCX 307KB\)](#) advice and Agency Response to the Minister for the NDIS and the DRMC, in keeping with Section 145 of the NDIS Act.
- The Intellectual Disability Reference Group further worked on finalising their input to the IAC's advice 'Enhancing behaviour support in the NDIA'.
- The NDIA progresses the Home and Living Framework and Implementation Plan, co-designed with the IAC, to the NDIA Board.
- Dr Ben Gauntlett concludes his role as Disability Discrimination Commissioner, also leaving his IAC role as Expert Adviser.

# 9. Advice to the NDIA Board and input into NDIA co-design

## 9.1 Advice to the NDIA Board

The IAC's purpose and statutory role is to give advice to the NDIA Board about the delivery of the NDIS. This is a part of Section 144(1) of the NDIS Act. The Board must consider our advice, along with an accompanying Agency Response detailing the implementation of our recommendations. Our advice, along with the Agency Response, is also sent to the Disability Ministers.

Our advice to the NDIA Board is presented as a report. Our Independent Consultant compiles the perspectives of our members to shape this report. We engage various viewpoints in our advice, collaborating with Reference Groups, external stakeholders, individuals with disabilities, researchers, and sector experts.

This year, our advisory efforts encompassed:

1. Submission of the [Improving equity in the NDIS \(DOCX 307KB\)](#) advice to the NDIA Board, accompanied by an Agency Response.
2. Creation and endorsement of the advice 'Improving the NDIS for children and young people: the importance of being guided by their voice'.
3. Development of 'Enhancing behaviour supports in the NDIA'.
4. Tracking how the NDIA is implementing our advice, including reporting, and monitoring the progress of historical and current IAC advice.

Over the years, [we have generated a broad range of advice accessible on IAC's website.](#)

### 1. Improving equity in the NDIS – what is it about?

[Improving equity in the NDIS \(DOCX 307KB\)](#) aims to enhance the fairness of the Scheme through support for people seeking to join the NDIS and achieve their goals. This advice relates to ensuring equal access, participation, and outcomes for all NDIS participants, especially those identifying as First Nations, CALD, and/or LGBTIQ+.

Our collaboration with the IAC Equity and Inclusion Reference Group played a pivotal role in crafting this advice. Insights from engagement with leaders within diverse disability community groups significantly enriched and moulded our advice.

The advice advocates for a renewed and co-designed approach to achieving long-term equity in the NDIS. It highlights the need for a **whole-of-government approach**, encouraging different government agencies to collaborate in supporting people with disability and improving equity outcomes.



The advice strives to ensure that the Scheme fosters a sense of cultural safety for people with disabilities and, where applicable, their families. This entails the right to feel secure within the NDIS, regardless of cultural background, gender identity/expression, biological sex, sexual orientation, and attraction.

In May 2022, the IAC endorsed [Improving equity in the NDIS \(DOCX 307KB\)](#). The Board received the advice and Agency Response in March 2023, approving the Agency Response and acknowledging their support for all IAC advice recommendations.

Aligned with IAC governance processes outlined in the NDIS Act, both the advice and Agency Response were submitted to the Minister for the NDIS and the DRMC. The NDIA remains committed to collaborating with the IAC and the disability community to implement our recommendations.

## **2. Improving the NDIS for children and young people: the importance of being guided by their voice – what is it about?**

The goal of the advice ‘Improving the NDIS for children and young people: the importance of being guided by their voice’ is to enhance the NDIS experience for children and young people with disabilities, enabling them to thrive within families and communities.

Developed in consultation with the IAC Children, Young People, and Families Reference Group, the advice emphasises the human rights of children and young people. It acknowledges the challenges faced by this growing cohort of NDIS participants whose outcomes aren’t always being met.

As a result, the advice stresses the importance of involving children and young people in shaping ways to enhance NDIS support for better outcomes. This encompasses their participation in influencing new NDIS policies and determining the use of their NDIS plans.

The advice contends that the NDIS should invest effort in understanding and addressing the unique requirements of children, young people, and young adults. This includes recognising the distinctions across life stages and the additional difficulties posed by intersecting hardships.

In May 2023, the IAC endorsed this advice. The NDIA will craft an Agency Response to this advice later in 2023. The IAC will adhere to governance procedures in presenting the advice and response to the Board, Minister for the NDIS and the DRMC.

### 3. Enhancing behaviour supports in the NDIA – what is it about?

The advice 'Enhancing behaviour supports in the NDIA' originated from the IAC Intellectual Disability Reference Group. It explores ways in which the NDIA can enhance behaviour supports for people with disability who show concerning behaviours, including those that might harm their own wellbeing or that of others.

Our goal with this advice is to ensure that behaviour supports follow **best practice** and offer participants increased choice. Best practice encompasses services informed by expert advice and proven research. These supports aim to understand the underlying motivations of behaviours.

The advice advocates for trauma-informed and empathetic best practice supports. The focus is on addressing the root causes of behaviours rather than restraining the resulting actions. The advice also highlights the importance of acknowledging participants' experiences as part of their supports.

The IAC will consider finalising this advice in the first quarter of 2023-24, after which the NDIA will develop an Agency Response to the advice.

## 9.2 Input into NDIA co-design

Throughout this year, we've engaged in 4 significant NDIA [co-design projects](#). Our members have contributed expertise across various steering committees and helped engage the disability community. Together, we've refined NDIA's co-design work, providing participant perspectives and expert insight through **iterative** engagement and project development.

Key co-design projects we've been involved in include:

### 1. Home and Living Framework and Implementation Plan

Working as part of a co-design steering committee, IAC and Home and Living Reference Group representatives collaborated with the NDIA to craft a comprehensive Home and Living Framework and Implementation Plan.

Our participation extended to research and co-design activities alongside a diverse design group, including participants, disability support providers, and representative organisations. We also undertook a trial of the framework with underrepresented people with disabilities. Our focus remained on advocating for participants' autonomy and control over their living arrangements and support.

We are pleased that the NDIA sent the co-designed work to the NDIA Board in June 2023, and we look forward to its future public release.

## 2. Supported Decision-Making Policy

A sub-group of IAC and Intellectual Disability Reference Group members played integral roles in supporting NDIA co-design work for supported decision-making. Operating within a co-design steering committee, we gave feedback on consultation papers and actively participated in co-design workshops, many of which were led by individuals with disabilities who are also NDIS participants.

Through these efforts, we progressed a comprehensive understanding of the challenges people with disability face in making their own choices. Our exploration included complex communication needs, First Nations people in remote communities, CALD individuals, those with psychosocial disabilities, and LGBTIQ+ individuals.

The result of these insights led to the NDIA's publication of the [Supported Decision-Making Policy](#) in May 2023, serving as a guiding resource for NDIS participants seeking control over their lives.

## 3. Participant Safeguarding Policy

We're proud to have contributed to the co-design of the NDIA's [Participant Safeguarding Policy](#). This policy, released in April 2023, evolved from recommendations based on our advice [Choice and control to safely live a good life of belonging and citizenship \(DOCX 1MB\)](#).

IAC representatives were instrumental in the project's co-design steering committee and virtual workshops, held between June and October 2022, involving diverse target groups. These forums shaped crucial aspects of the Participant Safeguarding Policy and Implementation Plan. The NDIA's inclusive approach engaged individuals from varied backgrounds and experiences, and was uplifted by research and tailored engagement strategies.

Aligning with our advice, this co-design project reaffirms our commitment to aligning choice, control and safety, with the essence of belonging and citizenship.

## 4. Information Gathering for Access and Planning

Our involvement in co-design for Information Gathering for Access and Planning started with a focus on establishing a shared understanding and evidence base about the current state of NDIS access and planning.

Our IAC representatives actively participated in the co-design steering committee and laid the groundwork, including engagement with participants and health/allied health professionals, as well as in-depth assessments of NDIS legislation and operations.

Given the alignment of this project with the NDIS Review, NDIA's focus has shifted towards short-term enhancements for this work, such as redesigning forms and templates for information collection, while awaiting NDIS Review recommendations.

## 10. Word list

**Agency Response:** A response statement by the NDIA explaining what they will do to make sure IAC advice and/or recommendations are put into practice, to improve the NDIS.

**Best practice:** Services that follow expert advice, and that research has shown to work well.

**Co-design:** When all the people involved in delivering, experiencing and understanding a system work together to make it better. For example, people with disability work with the NDIA to help make the NDIS work better for people with disability.

**Governance:** The system for running an organisation, including who is responsible and accountable for each part of the work.

**Intersectionality:** Some people are different in more than one way. For example, they may have disability and identify as First Nations people. Intersectionality happens when they are treated differently or poorly for all the ways they are different.

**Iterative:** Improving work or a product/service by using a process that includes feedback, and allows for further refinement.

**Operating Model:** A process that defines how we will work to achieve our aims and deliver advice.

**Stakeholders:** Are all the people directly or indirectly involved in an issue or piece of work.

**Sustainability:** Ensuring that something can run for a long time without costing too much.

**Systemic:** A problem or change in policy and/or practice that affects, or has the potential to affect, many people.

**Trauma-informed:** Care that lowers stress levels and reduces the likelihood that people who have experienced trauma will be overwhelmed.

**Whole-of-government approach:** Different government agencies working together to address issues that cut across different areas of government. For example, people with disability may need disability support in the health, justice and education systems.

**Work Plan:** Outlines and plans our priorities and what issues/opportunities we will focus on over a set amount of time. For example, our Work Plan usually runs for one year.

## 10. Word list

### 10.1 Acronyms

<b>CALD:</b>	Culturally and Linguistically Diverse
<b>CEO:</b>	Chief Executive Officer
<b>DRCOs:</b>	Disability Representative and Carer Organisations
<b>DRMC:</b>	Disability Reform Ministerial Council
<b>IAC:</b>	Independent Advisory Council
<b>ILO:</b>	Individualised Living Options
<b>LGBTIQA+:</b>	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer or Asexual Plus
<b>NDIA:</b>	National Disability Insurance Agency
<b>NDIS:</b>	National Disability Insurance Scheme
<b>SDA:</b>	Specialist Disability Accommodation.



**Independent  
Advisory  
Council**  
to the **ndis**

Independent Advisory Council to the NDIS

[advisorycouncil@ndis.gov.au](mailto:advisorycouncil@ndis.gov.au)

[ndis-iac.com.au](http://ndis-iac.com.au)